

Steps to Home

Parents as Partners throughout
the Neonatal Journey

Baby's name:

Baby's date of birth:

Baby's NHS number:

Baby's hospital number:

Patient information

Welcome to our Neonatal Service

Your baby has been admitted to our Neonatal Service within Brighton and Sussex University Hospitals NHS Trust. We have two neonatal units: the Trevor Mann Baby Unit (TMBU), a regional Neonatal Intensive Care Unit at the Royal Sussex County Hospital in Brighton and the Special Care Baby Unit (SCBU) at the Princess Royal Hospital in Haywards Heath. Our neonatal units are two of fourteen neonatal units that form the South East Coast Neonatal Network across Kent, Surrey and Sussex.

We understand that this is likely to be a very challenging time for you and your family and the neonatal team within our Network will do their very best to support you at this time. We are strongly committed to providing excellent, family centred, compassionate care to all babies and their families.

Our units here in Sussex provide care to high risk, often critically ill neonates and family integrated care is one of our guiding principles. We understand and believe that even the best medical care cannot replace your presence and the love you can provide to your baby.

The aim of this booklet is to give you guidance and support throughout your neonatal journey. The seven chapters follow the timeline from admission to discharge and enable you to highlight the milestones and achievements of your baby and give you somewhere to record your skills and competencies. The overarching goal of family integrated care is to support parents in becoming equal members of the neonatal team and participate in providing active care for their infant. We hope to empower you to become an expert in your baby's care, enabling you to become confident parents.

The IFDC (Integrated Family Delivered Care) mobile application (see appendix for more details) contains useful material to help you to prepare for and engage with this journey.

The **Small Wonders** videos are a series of films that contain useful information about having a baby on a Neonatal Unit. These can be viewed on the website <https://www.bestbeginnings.org.uk/small-wonders>

South East Coast Neonatal Operational Delivery Network

There are fourteen neonatal units within the South East Coast Neonatal Network indicated on the map below. Once intensive care is no longer needed your baby's care may be continued at our Special Care Baby Unit in Princess Royal Hospital in Haywards Heath or within a different hospital within our network. This will be discussed with you, if it is appropriate for you and your baby. Ongoing care will usually be provided by a hospital that is closer to your home.

If you live outside the network, we will let you know which network covers your local area and will liaise with the appropriate hospital for continuing care.



How will my baby be transferred?

Our South East Coast Neonatal Network has three neonatal transport teams that together provide a 24/7 service for our region and beyond. They perform emergency transfers for sick babies requiring specialist care and also repatriate babies for ongoing care closer to home. The three neonatal transport teams in our Network are based in Kent, Surrey and Sussex with our local team operating from the Trevor Mann Baby Unit in Brighton. Each specialist team has its own dedicated neonatal ambulance and a specially designed transport incubator equipped to care for the sickest babies during transfer.

Our neonatal doctors and nurses will only transfer your baby if we feel your baby is ready and we will liaise with the referring centre so that information relating to your baby and their care is handed over. It is sometimes possible for a parent to travel in the ambulance when your baby is transferred but this can vary depending on the condition of your baby and the transport team's local policies. The photographs below show some of the equipment we use to transfer babies.



Me and my family

My baby's name		
My baby's date of birth		
My baby's hospital number		
My baby's NHS number		
My baby's gestation at birth		
My baby's birthweight		
My baby's hospital of birth		
My baby's hospital for continuation of care		
My baby's named Consultant		
Parent names		
Parent contact numbers		
Sibling names		
Home address for discharge		
My baby's GP name		
My baby's Health Visitor's name		
My baby's Health Visitor's contact number		

Special memories and my baby's 'firsts'

A large white rectangular area for writing, centered on a background of horizontal stripes in various colors (green, grey, pink, blue, yellow). The stripes are arranged in a repeating pattern: green, grey, pink, blue, grey, pink, grey, green, grey, yellow, grey, green, grey. The white area is intended for the user to write down special memories and their baby's firsts.

Watch Small Wonders films 13 and 6
Read chapters 2 and 5 of the
Integrated Family Delivered Care
[IDFC] app

Early days

Helpful things for you to do in the early days	Date completed
Understand the importance of good hand hygiene to prevent infection	
Take a tour of the neonatal unit	
Become familiar with the daily routine of the unit e.g. ward round, visiting times	
Become familiar with the multidisciplinary team caring for your baby	
Become familiar with the use of expressing equipment	
Become familiar with the IFDC mobile application	
Find out about the parent education sessions	
Learn about presenting your baby during ward rounds and take part in discussions	
Find out what to do if you have a concern, question or complaint	

Watch Small Wonders films 4 and 7
Read chapters 9 and 14 of the IFDC app

Expressing your breast milk

Expressing your milk and establishing lactation early is beneficial for both you and your baby	Process explained or demonstrated	Able to perform with support	Performs independently
I have an expressing kit and know how to perform breast massage and hand expression			
I know how to use a breast pump and clean it after use			
I know how to wash, rinse, dry and store my expressing kit			
I can label, store and transport my milk safely			
I understand the importance of expressing 8-10 times a day, including at night between 2-4 am			
I understand the value in recording my milk volumes using the mobile app or paper log			

Watch Small Wonders film 6
Read chapters 3, 4 and 12 of the IFDC app

Caring for your baby

Being actively involved in your baby's care means you will be prepared for home	Process explained or demonstrated	Able to perform with support	Performs independently
I can provide mouth care and positive oral touch for my baby			
I can provide skin and eye care for my baby			
I can change my baby's nappy			
I can dress/undress my baby if they are wearing clothes			
I can make my baby's bed or nest			
I can assist with changing the oxygen saturation probe site			
I can take my baby's temperature and discuss what to do if my baby is hot or cold			
I feel comfortable taking my baby in and out of the incubator or cot			
I can give my baby a skin to skin cuddle			

Watch Small Wonders films 5 and 6
Read chapters 12 and 13 of the IFDC app

Feeding your baby

Being involved in feeding your baby and helping them to develop their suck will help your baby feed	Process explained or demonstrated	Able to perform with support	Performs independently
I know how to check my baby's milk with the nurse			
I know how to prepare and warm my baby's milk			
I know how to check the pH of my baby's feeding tube and show the nurse before starting a tube feed			
I know how to hold my baby's syringe of milk during a tube feed			
I know how to perform exercises to develop my baby's suck reflex as shown by the SALT team or nurse			
I am aware of my baby's cues when they show me they are hungry and ready to feed			
I am aware of the benefits of non-nutritive sucking			
I am able to position my baby at the breast and recognise an effective latch and milk transfer			
I know how to prepare and give a bottle feed safely if that is my chosen method of feeding			

Getting to know your baby

Understanding the basics of developmental care can help both you and your baby	Process explained or demonstrated	Able to perform with support	Performs independently
I understand the principles of developmental care and know how to move through these as my baby develops			
I understand the benefits of skin to skin cuddles and know how to do this and record it on the app			
I understand the importance of early communication by talking, reading and singing to my baby			
I know how the importance of changing my baby's position at suitable intervals			
I know how to place my baby in the optimal position in their incubator or cot			
I understand how to prepare my baby for interaction and to interpret signs that show they are ready			
I understand signs of stress or discomfort e.g. frequent hiccoughs or yawning, splaying hands, arching			
I understand how to comfort and support my baby through difficult procedures and handling			

Watch Small Wonders films 8 and 9
Read chapter 11 of the IFDC app

Medicines and immunisations

Understanding the medicines that your baby needs helps to prepare you for home	Process explained or demonstrated	Able to perform with support	Performs independently
I am aware of the medications that my baby is receiving and I understand what they are for			
I have had the opportunity to practice giving my baby their medication			
I know how to obtain any medicines that my baby needs once we are home			
I know when my baby is due their immunisations			
I have any special equipment that my baby needs at home			

Watch Small Wonders films 8 and 9
Read chapter 15 of the IFDC app

Preparing for home

Things to complete in preparation for going home	Process explained or demonstrated	Able to perform with support	Performs independently
My baby has been moved to an open cot			
My baby no longer requires monitoring or a heated mattress			
I have registered my baby's birth			
I have registered my baby with a GP in my local area			
I have my baby's 'Red Book' or Child Health Record			
I have completed my Infant Basic Life Support training			
I know about the importance of safe sleep			
I have been given the EI SMART leaflet for 0-3 months or other appropriate developmental exercises for my baby			
My baby's medication has been ordered ready for home			
I have been given a letter for my GP to obtain special formula milk, if my baby requires this following discharge			

Going home

Things to check before you go	Process explained or demonstrated	Able to perform with support	Performs independently
I have been given a copy of my baby's discharge summary and this has been explained to me			
I am aware how to access breastfeeding support and advice once we are home			
I am aware how to access general support and advice once we are home			
I understand the role of the Neonatal Outreach Community team and know how to contact them, if required			
My baby has had a hearing test			
My baby has had an eye check, if required			
My baby is up to date with all newborn blood spot screening tests			
My baby has had a physical check by a doctor before discharge			
My baby has been weighed and had their head circumference measured before discharge			
I have the medications and any special formula milk that my baby requires at home			

Appendix

Integrated Family Delivered Care mobile application

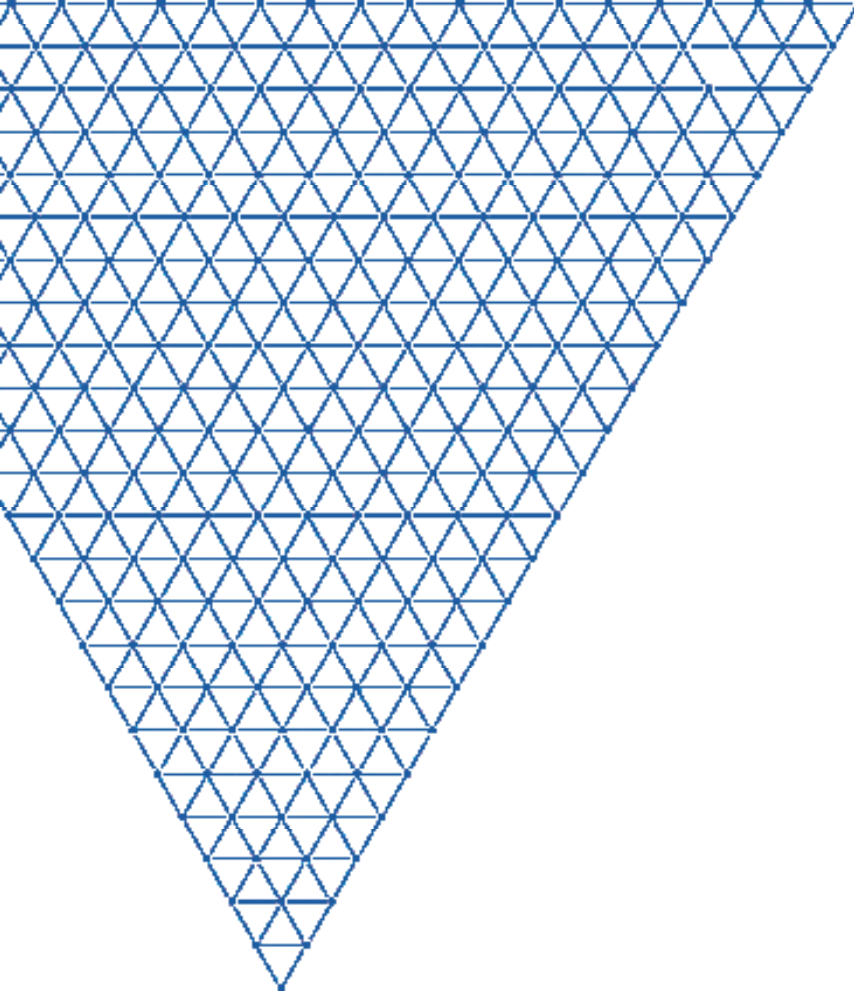
The overarching goal of family integrated care is to support and empower parents to become equal members of the neonatal team and participate in providing active care for their infant. We believe that even the best medical care will be enhanced by the love and support that you can provide to your baby.

With the help of the IFDC mobile app, our rolling education programme and this booklet, we hope you will feel actively involved in your baby's care while they are on our neonatal unit. These educational materials have been designed to support you through your time on the neonatal unit.

The app is free to download using the QR code below or by searching IFDC in the app store on your smart phone.



For more information and resources, please check our website <https://www.bsuh.nhs.uk/tmbu/>



Acknowledgments

Adapted for UHS Neonatal Services with kind permission from North West London Perinatal Network

**This leaflet is intended for patients receiving care
in Brighton & Hove or Haywards Heath**

Ref. number: 2107
Publication date: 04/2022
Review date: 04/2025

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